

CONVERSION TO A POLICY OF  
COMMUNITY PRESENCE AND PARTICIPATION

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for him who can discern it, and  
centrally and simply, without  
either dissection into science,  
or digestion into art, but with  
the whole of consciousness,  
seeking to perceive it as it  
stands....

James Agee, 1939

During the depths of the Great Depression, a writer, James Agee, and a photographer, Walker Evans, traveled through the deep south to study the conditions of tenant farmers. Their period of immersion in the lives of an extended family of destitute dirt farmers was described in a remarkable book with an ironic and bitter title: Let Us Now Praise Famous Men. The power of Agee's "report" was generated by his ability to alternate between journalistic description and poetic imagery, as if at one moment he were giving the reader a weather report, abruptly followed in the next by throwing him bodily into the full force of a raging hurricane, then back to the isobars and rainfall amounts. Perhaps at the conclusion of the book the reader knew not what to do about the forces of poverty and power and powerlessness, but he certainly knew a bit more about which way the wind blew and how it felt.

It's a rare intellect that can be immersed in a storm and –simultaneously– rise above it to a height sufficient to describe its shape and course. A portrayal of public policy toward this mix of conditions called "developmental disabilities" deserves an intellect of Agee's stature. To state what will become

obvious later on, I'm not the person to do full justice to the task. My only consolation is that I suspect no one else is really up to the job either, although a few have come close.

Like many other young professionals at the time, I drifted into this region called developmental disabilities just as the storm was gathering force, a little over a decade ago. I've been immersed in it ever since. I'm immersed by choice, however (that is, like Agee, I could leave it). The people who are truly immersed are those who live with the identity of being developmentally disabled and their families. I can't pretend to represent their experience, but I can share a partial list of forces that often flood my thinking and confound my efforts to comprehend their predicament:

the clash of unspoken assumptions; the muddled semantics of program and people labels; "programs" defined by their activity, and not their outcomes or intent; waste of resources and the spoilage of human opportunity; the politics of disability; the economics of disability; disabling professionals; prejudice and folklore posing as science; tactics of institutional decentralization that perpetuate strategies of human confinement; systematic reward of incompetence; demands for lowered expectations; cries that the solution equals more money; We's and They's.

The items on this list are strong and pervasive; their roots are deep. The list contains no possibility of joy or cause for celebration.

But the presence of a storm suggests both forces and counter-forces. And, indeed, there is a second list, one that contains exhilarating possibilities. A recognition of these forces shall keep us from throwing up our hands in defeat:

the emergence of self-advocacy on the part of persons with disabilities, such as the People First movement; increasing eagerness on the part of young professionals to examine the nature of values as a controlling framework for the application of their science and technology; the invention of new, or "implied", rights (to education, to habilitation, to services in the least restrictive environment); new legislation and litigation that codify these implied rights; an increasing willingness to take a hard look at the role of handicapism in our cultural mores and traditions; islands of remarkable leadership and risktaking within our state and federal bureaus and our universities; a desire on the part of some workers and organizations to provide competent services in spite of bureaucratic expectations to the contrary; parents who are no longer thankful for small charities, but are demanding rightful services for their sons and daughters.

Notice that my list of enervating forces contains terms intended to suggest that these forces of possibility are young and vulnerable, each susceptible to diffusion and revision.

People with developmental disabilities, their families, and their friends are all caught up in the tension and frustration

created by these oppositional forces. That is  
order to manage the energy created by this tension, energy that  
can fuel constructive change, we must gain a little altitude on  
the flux now and then to see the broad social terrain a bit  
better. Otherwise, we'll continue to be buffeted along by  
opposing forces with no comprehension of where or why.

#### A Statement Of Minimum Ethics

We don't have to like one another  
...but we do have to put up with  
each other,

Kathryn Hepburn, 1979  
(overheard in a television interview)

It strikes me that Ms. Hepburn's imperative that we must,  
at the very least, put up with one another represents a funda-  
mental ethical statement that is lodged at the very core of the  
Constitution of the United States. Thus, I may not like what you  
have to say, but, regardless, I have to put up with your freedom  
to express it. You may not like my skin color, religion, ethnic  
origin, or gender, but, regardless, you have to put up with my  
children going to school with yours and the possibility that the  
bunch of us might occupy the house next door to yours. And so on.

Now we know also that the Constitution doesn't say that we  
have to put up with anything others might say or do. Some acts  
exceed the bounds of permissible latitude. The determination of  
the boundaries between those acts we have to put up with and those  
we don't is assigned to our legislatures and our courts, both of

which are supposed to regulate our actions in compliance with constitutional protections of individual latitude.

Disregarding probation and death, the citizen whose acts are found to exceed the bounds of what others have to put up with faces two types of consequences: fine and confinement. The former penalty extracts something of value from the person but allows him to remain in the larger community. The latter penalty – confinement– results in removal from the larger community, deprivation of rewards, and grave restrictions on the opportunity to act even within the range of behavior allowable in the larger community. Acts that justify confinement are taken to be so serious that we cannot even put up with the possibility of the act being committed again, at least not for a certain period of time.

In practice our marvelous Constitution hasn't worked out perfectly for all citizens all of the time. We're aware, for example that some citizens "get away" with acts that would not be put up with in others. And we know that some people have been confined away from the community-at-large not because of acts that exceeded legal codes of conduct but because of who they were. Perhaps the most enduring and vivid case in point is the history of America's "treatment" of that group of its citizens called developmentally disabled. Ms. Hepburn would be appalled if she knew.

## The Policy Of Confinement; Its Roots. Its Consequences

The topic of this paper is not focused on institutions, per se, or the current state of "de-institutionalization". However, it is impossible to pursue our attempt to comprehend the tension between oppositional forces present in our land today without some clarity about the history of the institutional model and its seminal rationale.

The confinement of persons with developmental disabilities has taken many forms and disguises. The most blatant expression of systematic confinement is the large, self-contained, state institution. As a model of human management, the state institution in America has had a checkered history over the last century and a quarter. Tortured rationales for its legitimacy came and went until about 1925, when—as Wolf Wolfensberger proposes—the rationale for institutions could no longer be sustained, even though their perpetuation and expansion continued to drift unchallenged until the 1950s. Unfortunately, the last "rationale" for state institutions to fade before the "drift" era began was based on the assumption that persons called "feeble minded" (as well as other "defectives") constituted a menace to the community-at-large. Spokesmen from the professions (please note) had convinced the citizens that some persons, as an unavoidable consequence of the nature of their condition, posed a grave threat to the genetic pool and to the moral integrity of the community itself. The institution was designed in both its architectural and organizational structure, therefore,

to serve the purpose of isolating a menace to society at the lowest possible cost. The menace this class of people represented could not be put up with; the solution of confinement as a deterrent was irresistible. The shrill of the menace indictment faded away after about 1925, but no voice of authority came forward to offer new rationales or new approaches to human management until many years later. Tragically, we have inherited the model created by the menace rationale, and we're still divided as to what to do with our institutional legacy.

The institutional legacy has little to do with the architecture and walls we associate with the word "institution"; except to the extent that the architecture is a consequence, or shadow, of a set of assumptions about the nature of developmental disabilities— especially the nature of that sub-category called mental retardation. It was the set of fundamental assumptions ("limited potential", "sexual menace", "perpetual child" —all compressed in the character, Lenny, in Steinbeck's Of Mice And Men, who "didn't know his own strength") that led to a public policy of confinement that led, in turn, to the architecture we think of as the institution. If we were a little more precise in our choice of terms, we'd refer today to policies of de-confinement (or, as one friend insists, "re-patriation") rather than de-institutionalization. One of the "seeds of perversion" to which Wolfensberger has referred lies in our failure to examine the roots of the policy we inherited as much as we do to its bitter fruit. That failure has allowed the translation of the policy of confinement into more subtle forms in recent years:



"special" schools, segregated employment, long-term group homes with no exits, reserved hours at the YMCA pool, and on, and on.

With a little altitude over our "field" of developmental disabilities, it is a bit easier to see that yesterday's solutions constitute today's problems. Perhaps this cycle is inevitable, in some cosmic, deterministic scheme. Perhaps not. The only way we can hope to impinge on a problem-solution-problem cycle, I believe, is through constant attention to fundamental assumptions. If the assumptions are, in fact, different, then the public policy they create and the expressions of that policy in the workings of law, government, education, and the patterns of everyday life will also contrast sharply with past and current "treatment" of this part of our population.

The Roots Of A New Policy Of Community Presence And Participation

A number of observers have noticed that in order for a systematic policy of human segregation to "work", the class of people who bear the brunt of separation somehow must be defined as "non-human". In order for the "menace", rationale to spawn the policy of deterrent confinement, the majority had to be reinforced in a belief that persons with developmental disabilities were non-humans, and, therefore, non-citizens. That process did, in fact, take place and was orchestrated by the "leading authorities" in the field of mental retardation at the time. If one thinks this summary goes beyond description and into

melodrama, I urge him or her to read Wolf ensberger's scholarly account entitled, The Origin and Nature of Our Institutional Models.

The policy of community presence and participation is new because it asserts humanhood for all persons with developmental disabilities. It's as simple as that, and as profound. The new policy that allows persons with developmental disabilities to join our "club" of humanity rests on two fundamental assumptions having to do with the nature of the person and the nature of the person's place in our society.

- Every individual possesses the capacity for continuous development.

- The birthright of American citizenship is not contingent on IQ or the potential quality of the citizen's body or performance.

These companion assumptions --neither more important than the other-- generate certain compelling questions: if we share membership in the same human and national club, how can those things valued by most of us be denied to some of its members? How can the privileges, protections, and rights of membership be withheld from some of the members without due process? And, very importantly, how can the club as a whole achieve excellence if some of its members are held back from what they could be? As loyal members, we must conclude that allowing inequities to continue for some of us threatens the worth of membership for all of us.

#### Expressions of the New Policy

The ascendancy of the new policy of community presence and participation suggests that a shift in basic ideology, in our

core structure of beliefs and values, is taking place— a shift possibly associated with changes in our system of law and our understanding of the nature of human performance. At best, one would describe these changes with reasonable accuracy and thoroughness. An attempt to draw conclusions about what fundamental shifts (if any) these changes express —about cause and effect, or coincidental correlation— would be patently premature. In this section, therefore, I'll take a middle ground and provide an incomplete description of changes in law and changes in our concepts of human performance as expressions of the new policy of community presence and participation. Even on the middle ground, I'm not absolutely certain which is an expression of which.

Law. It is generally agreed that the challenge to the policy of confinement first emerged in the early 1950s, when parents of disabled sons and daughters began to band together to provide some semblance of program activity for their offspring as an alternative to their confinement at home or their confinement in an institution, virtually the only two alternatives available at the time. The national organizations of parents and friends that grew out of this self-help expediency (such as the National Association for Retarded Citizens) created the base for a political movement. By the end of the fifties, NARC achieved its first success at attracting the attention of Congress to the federal neglect of persons with mental retardation. Congress responded by appropriating a small amount of funds for research and training programs. Federal legislation and funding accelerated following the election of President Kennedy, one of whose sisters

happened to have mental retardation. Relative to the baseline of virtually zero, the federal effort to stimulate research and services during the 1960s was massive. President Kennedy did for mental retardation something comparable to the impact he had on space exploration. (One is advised not to take that analogy too far, however.)

The momentum generated during the sixties was joined at the end of the decade by the introduction to America of a new concept: the principle of normalization. The term was coined by Bengt Nirje, then head of the Swedish Parents Association for Retarded Children, to describe the approach used in his country to promote and support the participation of people with mental retardation in the community-at-large. His description appeared in a book prepared for the President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded, published in 1969. Nirje told Americans that "the principle of normalization means making available to all mentally retarded persons patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society". Nirje went on to describe what that meant in terms of a normal rhythm of the day, normal holidays and celebrations with family, living in settings appropriate to one's age, in a sexually integrated world, with equal opportunities for education, training, and development. As Robert Meyer\*put it, "the concept is so natural, so simple, the approach so decent and humane".

As a co-editor of Changing Patterns. Wolf Wolfensberger did two important things: he contributed to the book his own laborious history of institutions in America which concluded with his call for a new "developmental model"; and, he edited Nirje's chapter on normalization which brought him into close inspection of the concept for the first time. The two chapters fit hand in glove. His work on the history documented the tragic consequences of de-humanization, while Nirje's chapter documented the limitless possibilities of re-humanization. The terrain of American services to persons with disabilities has not been the same since. Wolfensberger adapted the principle for American conditions and consumption, and —armed with his clear insight into the history of systematic de-humanization of people called mentally retarded—literally shook the apathy out of professionals and parents alike. It was at this time, at the turn of the decade, that the storm began to gather its force.

The intellectual and emotional impact created by the normalization movement during the 1970s can be seen clearly in the significant increase of public interest lawyers taking to the courts to establish new precedents for assuring the rights of persons with disabilities. Concurrent with the advocacy litigation, landmark federal legislation —incorporating the assumptions and language of normalization— was adopted by Congress.

Because of space and scholarship limitations, I will not attempt to review here the significant judicial and legislative breakthroughs that are re-shaping our human service concepts

and systems. The best single source I know for a wide-ranging picture of this dynamic field of disability law is, The Mentally Retarded Citizen and the Law. Published in 1976, this book was exhaustive to the time of its publication; but the field of disability law is moving so quickly that it is already out of date with regard to a couple of major developments.

While foregoing a legal review, it would be useful to illustrate the rapidity with which the birthright of citizenship is being affirmed for children and adults with disabilities.

During the first half, of this decade, my duties as an administrator in a large, comprehensive, service system in eastern Nebraska included the development and oversight of educational services for a substantial number of children with mental retardation. Over half of these children were of public school age. Our agency served their educational needs because the public school boards and administrators chose not to: The purpose of our effort was to prepare "our" students to be good enough for acceptance by the public school programs.

It was in 1975 that the Federal Education For All Handicapped Children Act was signed, affirming the basic right to a free, appropriate, public education regardless of degree or type of disability. The Act was scheduled for full implementation in 1978— just last year. Think about it. Until just now, public education - a right most families take for granted-- was denied at will to thousands of children considered not worthy enough (human enough?) to claim education as their right, too.

The new federal law (also known as PL 94-142) goes further than "merely" requiring local schools to provide an educational program to all children; it requires that the child's education occur in the "least restrictive alternative". The law does not permit, therefore, a policy of exclusion to be converted to a policy of confinement. The separation of a handicapped student from his or her non-handicapped fellow students must be justified through due process and the student's own individual education plan. This Act is an exhilarating statement of moral and social principle. We should hope that the schools, the students, and their families figure out how to make it work.

The second illustration has to do with a powerful new tool in the arsenal of disability law, inelegantly known as Section 504 of Title V of the Rehabilitation Act of 1973. It's name may not be inspirational, but it's simple, concise language makes up for it:

No otherwise qualified handicapped individual in the United States... shall, solely by reason of his handicap, be excluded from participation in, be denied the benefit of, or be subjected to discrimination under any program receiving federal financial assistance.

Because this civil rights amendment was attached to a "rehabilitation" act, its full scope has been easily confused. Clarifying amendments to the Rehabilitation Act in 1974, however, made it clear that the protections and prohibitions under Section 504 are applicable to all handicapped individuals, and cover any federally-aided program (including vocational rehabilitation,

employment, housing, transportation, education, and health services). The implications of this amendment are so sweeping that it took a nationwide uprising of handicapped people to break the law's regulations out of HEW.

One of the most novel applications of Section 504 was its incorporation into a class action suit (Halderman v. Pennhurst State School and Hospital) that challenged the constitutional and statutory legality of the existence of large, segregated state institutions, such as Pennhurst in Pennsylvania. The case was brought before the U.S. District Court for the Eastern District of Pennsylvania in 1977, Judge Raymond J. Broderick presiding.

The evidence presented to the court regarding conditions existing in Pennhurst was overwhelming: mentally retarded residents confined to the institution received token habilitation programming, at best, and were in jeopardy of bodily injury as a condition of everyday life. On the basis of the record, Judge Broderick found that the Pennhurst resident's rights of equal protection and freedom from harm had been violated.

Judge Broderick, in his decision, found that

All admissions to state facilities, be it through court commitment, or otherwise, entail an infringement on fundamental rights and freedoms....Because of this, due process demands that if a state undertakes the habilitation of a retarded person, it must do so in the least restrictive setting consistent with that individual's habilitation needs.... isolation and confinement are counter-productive in the habilitation of the retarded. Furthermore, since the law recognizes that habilitation other than in the least restrictive setting is a violation of one's constitutional rights, there is no question that



Pennhurst, as an institution for the retarded, should be regarded as a monumental example of unconstitutionality with respect to the habilitation of the retarded.

Judge Broderick appears to be speaking to the constitutionality of isolation and confinement, irrespective of the quality of the "program" that may or may not be present within the perimeter of this most restrictive setting. In case the constitutional issue were not enough, Judge Broderick took notice that "In enacting Section 504 of the Rehabilitation Act of 1973, Congress has in effect codified the constitutional right to equal protection". Since he had found that the resident's Fourteenth Amendment rights to equal protection had been violated, it followed that their statutory rights under Section 504 similarly had been abused. Section 504, Judge Broderick held, "imposes affirmative obligations on state and local governmental officials and that under Section 504 unnecessarily separate and minimally inadequate services are discriminatory and-unlawful....the rights of the retarded at Pennhurst under Section 504...have been and are being violated". If Judge Broderick's decision survives all tests and becomes precedent, the illegality of the existence of virtually every large, public institution in the country will be open to challenge.

Section 504 and the Education of All Handicapped Children Act rest on assumptions that are diametrically opposed to the assumptions that produced the policy of confinement. These two laws alone will not guarantee the good life for persons

with disabilities. Rather, the laws guarantee that people who are not disabled, at the very least, have to put up with the inconvenience that may be brought about by disabled citizen's new access to the possibility of a good life.

Disability and human performance....

the more competence an individual  
has, the more deviance will be  
tolerated in that person by others.

Marc Gold, 1975

A common thread (and possibly the only one) that runs through this maze of categorical labels lumped together under the term "developmental disabilities" is a requirement for extraordinary learning resources. The requirement may stem from reduced body control (as with epilepsy and cerebral palsy), the dominance of competing, non-adaptive behavior (as with autism), or relative inefficiency of learning under instructional conditions sufficient for most people (as with learning disabilities and mental retardation). This general observation is contained in Marc Gold's "alternative" definition of mental retardation: "The mentally retarded person is characterized by the level of power needed in the training process required for him to learn, and not by limitations in what he can learn".

In contrast to definitions of disability that stress personal deficiency and ceilings on potential accomplishment, Gold's definition is essentially programmatic; that is, it tells what we must do (provide an adequate level of instructional "power") and not what the person with mental retardation will never ever

be able to do. The point of view implied by Gold's definition is fully consistent with the assumption underlying the "new policy" that every person possesses the capacity for continuous development. We can refine the assumption by adding that the rate at which development occurs and/or the level of resources required to manage and maintain development are what distinguishes developmentally disabled persons from others.

The developmental assumption, standing alone, would allow us to overlook a critical point, and that point is this: disability, deviance, and competence are social and relativistic concepts defined implicitly as they are by the community's values, the flexibility of its settings to accomodate deviation, and its readiness to allocate whatever training resources are required to permit a person to acquire performance essential to participation in its most common settings. The "diagnosis" of disability requires, therefore, an ecological analysis of the person's context—how the characteristics of the person interact with/what the environmental settings demand, expect, put up with, ignore, and are in short supply of. A definition of disability that dwells on personal characteristics alone will not be sensitive to the dynamics of person-setting interplay. A static definition of disability can itself be disabling.

(In eastern Nebraska, we implemented a policy of total integration of the young children we were serving by moving them and our teachers into regular preschool settings. After "our" children blended into the mob of typical young children, my clinical

skills deteriorated overnight. I had difficulty identifying "the retarded kids" from a distance. I had lost my cues that said if the child is in the mental retardation agency setting, the child must be retarded. The same thing happened when vocational training for adult clients was dispersed in regular industrial settings. In both cases, more happened than just a change in geography: the people began responding to the normal expectations of the setting; the setting adjusted to accommodate its new members; and I became increasingly more embarrassed during "tours" about the decay of my clinical skills of disability detection.)

Laws can be drawn to guarantee a disabled person's presence in the community, but no law can guarantee true participation. True participation will require the availability of extraordinary training resources, accommodation by natural community settings, and close attention to creating a positive balance between competence (valued performance) and deviance (that which draws negative attention).

Systems designed to serve the policy of confinement could properly ignore these issues. The new policy of community presence and participation, however, will need systems that look to the community-at-large for their reference points for both personal and program planning.

#### Summary

In this paper I have attempted –however superficially– to reflect the context of that mix of conditions called developmental disabilities "without either dissection into

science, or digestion into art". The condition of developmental disabilities requires science and is enriched by art; but first it needs comprehension. If we forego a comprehension of assumptions and history, an empirical summary of that context will tend to sterilize what is basically a human and moral situation, and poetry will tend to direct attention to style and away from comprehension. The path between the two is rich with possible keys to understanding, but is more demanding than I would have guessed. I arrive at this summary with no sense of completion or closure.

Especially for those who are not immersed in this context, I've tried to show that our nation is in the throes of conversion from a policy of confinement of persons with developmental disabilities to a policy of community presence and participation. The conversion from any fundamental premise to another unavoidably creates conflict; and, as we know from the history of politics, religion, and art, conversion contains the potential for self-destruction and perversion. The same conflict and potential is true in current efforts to convert the policy toward persons with disabilities. Resistance to the conversion stems, I believe, from (at least) three sources. First is the vested political, bureaucratic, and economic interests in the continued application of the policy of confinement. The second source results from, as Valerie Bradley puts it, "a failure to understand the essentially 'revolutionary', as opposed to 'evolutionary', nature of changes in care for developmentally disabled persons."

This failure leads to rejection of the legitimacy of the extraordinary short-run expenditure of money and bureaucratic effort required to convert from one system to another system. The third source of resistance comes from those people —many parents included— who are genuinely fearful that a mismanagement of the conversion will create a reality even more abusive than that produced by the policy of confinement we inherited. The fears expressed by those representing the last group, by the way, are far from groundless. Ironically, the compromises that may be seen as necessary to appease the first two sources of resistance are likely to produce the reality most feared by the third.

The course of conversion is fueled, as I tried to illustrate, by major developments in constitutional and statutory law. These recent federal laws and court decisions, although basically serving only to affirm the birthright of citizenship for Americans with developmental disabilities, are even now jolting our established systems to the core. As the spirit of self-advocacy grows among people with disabilities, we'll see that the jolts we're experiencing now in our schools, public services, and places of business are mild by comparison. The fruits of more than a century of neglect and handicapism will be difficult to overcome and replace in a short span of time. During that span, the quality of the preferred future will be at risk of following on the path of the "war on poverty" unless there is continual attention to the values and assumptions on which the new policy of community presence and participation is based.

I further tried to point out that the new policy requires a broader view of the relationship between disability and human performance. A static view of disability —one that dwells exclusively on the characteristics of the disabled person— will perpetuate the focus on reductive "treatment" of deviance with little attention left to the need for development of competent performance. The interaction between the characteristics of the person and the expectations, values, and tolerances of key settings in the community defines the nature of disability and the need for special resources. Response to the mandates of the new policy, as expressed by law, implies adaptation on the parts of both the persons with disabilities and the settings in which they achieve participation.

As the demand for participation in regular community settings expands, those who wield power in those settings ("decision-makers", to be polite) will inevitably call for a "needs assessment" as the first step in planning for the required accommodations. The first cut at a needs assessment does not require a statistical survey of special essentials. As co-citizens, people with disabilities need the same things you and I need: a decent place to live; family and friends who care; variety of experience; clear physical paths; challenge, risk, and a sense of accomplishment; interesting breaks in routine; and an adequate financial security free from the burden of charity. A life, in fact, that Kathryn Hepburn would approve of.

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